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ABSTRACT

A screening program at rural and urban Mississippi sites to determine developmental disabilities in young children (birth to 3 years) was carried out by community volunteers who had been trained to administer the Steps-Up screening instrument. Of 244 infants and young children who were screened within a 9 month interval, 76 children were rescreened and 37 failed the screening. Future directions of the rural site involve parent training and recruitment, and plans of the urban center to train a "core group" of local church volunteers who can continue screening in the community. (CL)

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DEVELOPMENTAL SCREENING OF INFANTS AND YOUNG CHILDREN UTILIZING TRAINED VOLUNTEERS - RURAL & URBAN MODELS

by

Paula Lawo, DiAnn Lewis, and James Mann

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The purpose of this project is to provide a developmental screening process for infants and young children using trained community volunteers. The screening of very young children for developmental disabilities is the first step in a continuum of services that includes diagnosis, case management, follow-up and finally, school placement. The program plan includes the following: (1) training of community volunteers who will then perform (under supervision) developmental screening of children age birth to 3 years; (2) selection of accessible community locations for screening sites; (3) referral of children identified as having a potential problem; and (4) case management follow-up of these children.

The project emphasizes early screening for large numbers of young children, coupled with a structure of systematic referral for diagnosis, treatment, and follow-up. The purpose for establishing early identification of infants and children with developmental disabilities is to minimize the negative impact of handicapping conditions for the child and to reduce the liklihood of expensive, perhaps less effective treatment later in life.

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I. Background

The developmental screening of infant and young children project - rural model, utilizing trained volunteers is a joint project of the North Mississippi Retardation Center, a university affiliated facility, only a few miles from the main campus of the University of Mississippi in Oxford, Mississippi, and the North Mississippi Methodist Agency For the Developmentally Delayed, an agency of the United Methodist churches of North Mississippi.

It was felt that a project involving churches of North Mississippi through their agency, the North Mississippi Methodist Agency For the Developmentally Delayed, and the major public mental retardation facility serving North Mississippi could provide a cost effective method for early identification of handicapped children. The strength of this project is seen in the involvement of local communities in the initial stages of identification, and in the increased awareness of handicapping conditions that this involvement produces. North Mississippi, with its rural area and thin resources, is an ideal model for testing the concept of using trained volunteers to perform gross developmental screening of young children.

The developmental screening of infants and young children project - Urban Model is a program of the Les Passees Rehabilitation Center of Memphis, Tennessee. The Center is involved in early identification of developmentally delay children and in evaluation, diagnosis, and treatment of those with central nervous system dysfunction or developmental disabilities.

When the project began in Memphis in 1978, Les Passees volunteers worked in several of Memphis' health clinics, screening babies and young children who had been brought in for their regular "well-baby" checkups. In an attempt to reach children who might not be receiving regular health checkups, the screening was switched from clinics to day care centers. Although a larger number of children were reached,

it was necessary to change directions once again. First, many of the children were not well enough known by the day care workers, and if a child was unwilling to perform a certain task required by the screening procedure, the worker was often unable to tell the volunteers whether the child could perform or not. Second, the follow-up testing was not satisfactory, as the child might not be present on the day Les Passees volunteers returned to rescreen those children.

In an attempt to reach children in a more "controlled" environment, and one that would benefit from the screening process, family day home services provided by the Porter Leath Children's Center in Memphis were used. The family day home services provides day care for young children in an individual's home, with a maximum of 6 children per home. The children in these homes are well-known by their day care mothers and Les Passees volunteers more easily make arrangements with the day care mothers to return for follow-up screening.

II. Review of Literature: Developmental Screening and Volunteer Services

Although much has been written as to screening practices for identification of specific disabilities, there appear to be only a few limited reports in the literature on screening infants and young children for developmental disabilities. After researching such sources as the computer files of ERIC and ECER, the information found points to a need for more assessment and utilization of developmental disabilities screening programs.

A recent report by Jaffe and others[1] indicates candidly the need for developmental disabilities screening. The results of a single Denver Developmental Screening Test performance at the age of 9 months on 823 infants attending maternal and child health centers were compared with the developmental information recorded by public health nurses during their routine well baby care of these same infants. The single Denver test detected a significantly greater number of infants with

developmental delay than did the routine observations, and the nurses tended to underuse the available resources for developmental assessment. Suggestions were made for more effective use of maternal and child health centers in the primary recognition of developmental delay.

Dinno[2] stresses the importance of early screening practices by discussing high risk predisposing factors which aid in early recognition of infants with developmental retardation or milder handicaps of educational importance. Listed are family history, prenatal, perinatal, and postnatal factors to consider.

Veda[3] reports that developmental differences in the Denver Developmental Screening Test items were demonstrated between Okinawa (615 Ss) and Tokyo (1171 Ss) samples of children (16 days to 6 years old). The Tokyo children were generally more advanced than Okinawa children after 1 year of age, while the Okinawa children showed earlier development in the middle and late periods of the first year. Other findings included that Okinawa children were initially slow in gross motor development, whereas Tokyo children were markedly advanced in some of the language items. Ecological and socio-cultural factors which may contribute to these differences were discussed, as were the implications of the results for developmental screening.

Many reports can be found dealing with screening measures for identification of specific populations. Holtzman's[4] report is designed for persons involved in the organization and regulation of screening of newborn infants for Phenylketonuria (PKU) and other genetic-metabolic diseases. It reviews new developments in the field, makes recommendations, and provides information about specific conditions other than PKU that are detectable by screening.

Steverson and Richman[5] screened one fourth of the total population of 3 year olds in a London borough for the presence of language delay and behavior problems. Boys were more likely than girls to have both language and general developmental

delay problems. Results emphasized the importance of investigating language delay in relation to nonverbal abilities.

Early identification of learning problems is explored by Wilbourn and Smith[6] by evaluating the Learning Problem Indication Index (LPII), an instrument intended to help identify the preschool child with potential learning problems. The screening test notes the presence of absence of certain perinatal events (such as difficult delivery) and developmental abnormalities (such as late walking).

In Downs'[7] report the goals, organization, and procedure of screening newborn infants for hearing losses are described. Goals are to identify newborn infants who have congenital hearing losses serious enough to handicap their speech and language development, identify the time of occurrence of the hearing disorder, and to facilitate study of the development of the hearing function in the human infant. The actual screening testing may be done by observant people, either professional or non-professional.

In contrast only one report on actual developmental disabilities screening programs was found. Jackson and others[8] tells of a screening program to identify developmental deficits in children between 2 and 5 years of age held in an economically deprived rural area. Community preparation consisted of media publicity and home visits by two indigenous workers. A community clinic day was established to assess each child's development in the following areas: medical and dental, cognitive and intellectual development, language development, socialization, perceptual-motor development, and self-help skills. Fifteen of the children were referred for further medical evaluation and 11 children for dental treatment. Each child 3 years of age or older met individually with a school psychologist and was tested on the Peabody Picture Vocabulary Test, the Visual Motor Integration Test, and the Goodenough-Harris Drawing Test. Ten of

the 22 children who were psychologically screened had two or more deficits and 10 children had one deficit. Mother-child and child-peer interactions were observed. Parents were invited to attend individual follow-up conferences. Preschool education was recommended for 18 of the children, of which 11 children were referred to a special education preschool class focusing on school readiness deficits.

Another program for infants at risk is suggested by Parmelee and others.[9] This report presents a cumulative risk score system designed to identify high-risk infants through multiple assessments over an extended period of time. The system scores prenatal, natal, and neonatal biological events and neonatal behavioral performance in an additive fashion. Infants are assessed in the first month of life to distinguish those babies with transient brain insult from those with permanent brain injury. At 4 months and 8-9 months of age the infants are again tested, primarily on a behavioral basis. The researchers were concerned with the later adaptation of the infant to his environment regardless of any biological deficit. Therefore, a child with motor or sensory handicaps who progressively compensates sufficiently so that he does well cognitively and affectively removes himself from the risk category. Five examples of the use of this system were presented. Intervention was advocated for those infants with persistent developmental problems which make them vulnerable to any adversity in their environment.

The topics of developmental disabilities and developmental disabilities screening can be found in different collections. A book edited by Darby and May[10] offers 14 papers presented at two conferences on assessment and intervention with handicapped infants, sponsored by the Western State Technical Assistance Resource. Titles and authors include: "Neonatal Diagnosis of the Neurologically Handicapped" (M. Colemen); "Principles of Infant Assessment" (J. Swanson); "Developmental

Screening Overview" (J. Meier); "Early Motor Development--Assessment and Intervention" (M. Swanson); "Infant Cognition--Considerations for Assessment Tools" (B. Darby); "Communication Development, Assessment, and Intervention" (N. Nichols); and "Social Development and Assessment" (P. Doyle).

The Meyer Children's Rehabilitation Institute[11] in Omaha, Nebraska presents an audiovisual lending library resource list of nine slide-tape packages, 13 videotapes, three 16mm films, and six booklets concerning educational and assessment techniques applicable to children from infancy to adolescence with physical or mental handicaps, learning disabilities, or developmental disabilities.

In Friedlander and others[12] Exceptional Infant: Volume III a section on the developmentally disabled child includes the following papers: "A Center for the Study of the Young Child with Developmental Delay" (J. Zadig et al); "Clinical Uses of the Brazelton Neonatal Behavioral Assessment" (E. Tronick et al); "Prognostic Value of Neonatal Behavioral Tests" (J. Rosenblith); and "An Intervention Program for Atypical Infants" (G. Nielsen et al). Contained in a section on the disadvantaged child is "Developmental Learning Approach to Infant Care in a Group Setting" (W. Fowler). Assessment is covered in the following chapters: "Is Early Intervention Effective?" (U. Bronfenbrenner); "Cognitive and Motivational Development in Early Childhood" (L. Yarrow et al); and "Notes on Language: Screening and Assessment of Young Children" (B. Friedlander). A section on screening presents "Screening: A State of the Art Survey" (B. Friedlander), and "Screening, Assessment and Intervention for Young Children at Developmental Risk" (J. Meier).

Meir and others[13] present papers from a 2 day conference in 1972 on screening and assessment of high risk children, 0 to 5 years of age, to detect developmental disabilities in physical, cognitive-intellectual, socio-emotional, and language areas. Briefly reviewed are legislation, reports, and programs which have concerned children's development in the last decade. Two papers consider physical screening

and assessment; one paper focuses on screening devices such as the Rapid Checklist; the other paper indicates preference for use of medical histories, developmental screening tests, and eye screening tests. Considered in the first of two papers on screening in the language area are issues and problems such as the primitive nature of assessment technique instruments; stressed in the other paper is the difficulty of screening for hearing ability. Touched upon in the summary of the conference's proceedings are such points as insufficient manpower for mass screening and expense.

This report brings up an important problem in screening procedures: manpower. In addition to aiding the professionals and children they work with, volunteer programs are good for the community. In a manual edited by Baucom,[14] Part 3 discusses the program functions that are most critical for advocacy--recruiting volunteers, screening and matching advocates and proteges, training, and follow along. General guidelines for using volunteers appear throughout the manual.

In recent years volunteers have been used and more in the field of Special Education. Buffer,[15] in a recent publication, discusses the use of retired individuals as volunteers in special education. Sections address common needs and interests of retired volunteers, considerations in recruiting volunteers, procedures for writing job descriptions, and volunteer training.

Genevois[16] reports that volunteers are used in homes for needy children (ages 0-18 years) in Brazil. Recruitment of volunteers is handled through press campaigns and a training course of 12 (3-hour) sessions emphasizing a sense of social responsibility and the importance of hard work. In one home alone over 300 volunteers work with the 500 children residing in the home. Many volunteers elect to take further training, learning such skills as the basic techniques of developing overall sensory-motor stimulation.

Outlined by Greer[17] are techniques for utilizing paraprofessionals and volunteers in special education instructional teams. Included are suggestions relating to the use of both volunteers and paraprofessionals in the following eight areas: organization (school system policy statements); finance (salary schedules); personnel classifications (teacher assistant, teacher aide, volunteer); recruitment (selection and training components); application (application forms, interviews); staff development (preservice and inservice education programs); coordination (central office administration); and evaluation and follow-up (evaluation teams, self evaluation, and program evaluation).

In most instances, volunteers need some type of training program. Siepker and others[18] describe a volunteer inservice training program in the psychiatric division of a children's hospital. Program components discussed include the selection orientation-interview, the emphasis on task oriented on-the-job training which focuses on the development of a narrow range of skills, close staff supervision, written evaluations, and volunteer department follow-up. Volunteer assignments highlighted are milieu therapy (recreation, craft, music, dance) and the administration of standardized intelligence tests under a psychologist's supervision. The program's success is attributed to the acceptance of the volunteers as vital to the hospital's overall program, involvement of hospital staff in training, careful planning, and team involvement.

Fabry and Reid[19] report success in utilizing this type of program. Five foster grandparents were taught training skills for use in their daily interactions with severely handicapped adolescents in an institution. Following baseline, specific teaching procedures consisting of teacher instructions, prompts, modeling, and praise were implemented. The grandparents' frequency of training three skill areas increased as the specific teaching was implemented in multiple baseline format.

The total amount of training continued as teacher instructions, prompts, and modeling were terminated and praise continued, although the grandparents spent their training time emphasizing only two of the three skill areas. Teacher presence was gradually reduced over an 11 week period, with no decrease in grandparents' frequency of training. Four of the foster grandchildren, all profoundly retarded and multiply handicapped, demonstrated progress throughout the study. Results were discussed in light of the available contributions of foster grandparents in institutional settings and maintenance of staff training.

Some communities may work toward inservice training by compiling a volunteer handbook, such as the Community Developmental School in Goldsboro, North Carolina has done. Baucom and others[20] have compiled a manual providing a curriculum for training volunteers in state protection and advocacy agencies, with particular emphasis on training volunteer advocates who have direct relationships with developmentally disabled people. The curriculum consists of five training sessions, each lasting about 2½ hours. The first page of every session gives an overview of the session and a list of necessary materials and preparations. Also contained are background materials, worksheets, masters for transparencies or charts, information on training activities, and resources.

Ludtke and Elliott[21] discuss a project demonstrating that volunteers, if properly trained, can extend the services of professional staff in a state residential institution for the mentally handicapped. There were 17 program areas in which volunteers trained by resident staff acted as aides or instructors. The program was considered a success with the following factors deemed most essential in the volunteer: an acceptance of the real purpose of his work, a sense of belonging, an opportunity to express his own ideas, job responsibility according to capability, understanding of what is expected, proper recognition of accomplishments, knowledge that goals are attainable, free access to volunteer staff for

conferences, and challenging assignments.

In summary, a number of studies and programs have been reviewed concerning screening for developmental disabilities and ultimately, the importance and potential of volunteers in these programs. All seem to point out the need for these screening programs. The importance of these programs is evident. Without early identification and subsequent intervention, developmentally disabled children, now and in the future, will not be provided effective early intervention strategies.

Also stressed was the value of trained volunteers. In many instances, programs would not exist without them. Of course the use of volunteers aids the children and professionals in many ways, but it also helps the volunteers and community by involving adults whose knowledge and experience might otherwise go to waste. In addition to these reasons, a volunteer program is worthwhile because of its public relations value.

After a search of the literature, some conclusions can be drawn. Early screening of developmentally disabled children is important, but is not yet a widespread practice. Few trained volunteer programs are utilized. Volunteers are cost effective and may be well worth the time and energy spent in their training.

III. Procedure

The screening program is open to any child, age 4 weeks to 3 years, whose parent or guardian consents to the developmental screening process. If, as a result of the screening, a possible developmental delay is noted, information on locations for complete diagnostic services will be provided. The project protocol calls for a reminder to be sent by mail to those parents approximately 3 weeks following the screening. Parents who elect to take their child to North Mississippi Retardation Center for evaluation by the Center's Diagnostic and

Evaluation Team automatically move into a case management system established by the Mississippi State Department of Mental Health.

In Memphis, the Les Passees volunteers refers the child who fails the test to an appropriate clinic to receive a comprehensive evaluation.

IV. The Screening Instrument

The instrument which is being used to screen these infants and young children is the Steps-Up screening instrument, developed at the El Paso Rehabilitation Center in El Paso, Texas for use with the infants and young children that were seen in the city of El Paso. This new instrument is designed to be used by trained volunteers to screen infants and young children for developmental delays.

Obviously a "gross" type of screening instrument, Steps-Up has provided an extremely simple tool to use with large numbers of very young children in a short span of time. It is not designed to replace such instruments as the Denver or the Utah screening instruments which require more highly skilled or technical volunteers to administer; but rather, Steps-Up was designed to enable a large number of children to go through a "gross screening" to determine developmental delays or potential delays and to single out "high risk" children who need to be followed with great care. The Steps-Up developmental screening may be easily administered by trained volunteers.

The Steps-Up screening instrument has nine questions on every card regardless of the age of the child being screened. These questions represent nine areas of developmental skills to be screened. They include: (1) gross motor skills, (2) fine motor skills, (3) speech and language, (4) cognitive social skills, (5) hearing, (6) visual, (7) head size, (8) hip displacement, and (9) seizures.

Each card represents a different set of criteria for a child of a particular age and functional level. There are thirty-two (32) cards in the set -- one for

each two weeks from 4 weeks, 6 weeks, 8 weeks, 10 weeks, etc. to 52 weeks; then every three months -- 1 year, 3 months; 1 year, 6 months; etc. up to three years.

Steps-Up screening has been utilized since 1976 and has been standardized from a sampling of more than 8,000 screenings. The authors of the Steps-Up material are currently in the process of packaging the Steps-Up material for marketing and distribution, including a complete manual on the Steps-Up plan, materials needed for screening, training of volunteers, etc.

V. Follow-up to the Screening

Screening by itself is of little value. It may provide an indication that a child is or is not able to perform certain developmental tasks which are normally expected of a child of that many weeks/months of age.

If a child is not able to perform certain tasks or functions, it does not mean that something is wrong with the child; it may simply be an indication that the child is a little slow in his/her development.

On the other hand, the failure to be able to perform certain developmental tasks may be an indication that there could be a problem, that a child could possibly have a serious developmental delay. If so, then the earlier it is determined exactly what the problem is, the more can be done for the child to help him/her minimize the "problem" and to maximize his/her own potential.

Screening does not determine what or if something is wrong. Screening only indicates that a child may or may not be able to perform certain developmental tasks at certain age levels when those particular developmental milestones are expected. If a child fails the Steps-Up screening, he/she will be referred directly to a child/development center diagnosis or evaluation clinic in Memphis or to the North Mississippi Retardation Center Diagnostic & Evaluation Center for a detailed evaluation.

VI. Results from Steps-Up Screening

During the first nine months of the Steps-Up screening program at the Meharry Medical College in Nashville (April-December, 1979), 244 infants and young children between the ages of 4 weeks and 3 years were screened by volunteers who have been trained by one of the authors of the Steps-Up screening program. Of this number, 76 "passed questionably" which means that while they did not fail, their performance level on the various developmental milestones left questions about their functional or developmental skills. Such children who "passed conditionally" are rescreened to be sure whether the child has a developmental delay or whether the child is just simply "slow" in certain areas of development. Of the 244 infants and very young children screened through the Pediatric Private Practice Group Clinic at Meharry, 37 of the children or approximately 15 percent of the "controlled" sample failed the Steps-Up screening.

The Steps-Up developmental screening program is also used by Les Passees Rehabilitation Center in Memphis. The Les Passees volunteer project has kept statistics on children who have been screened by the Les Passees Volunteer program and the results are reported in the following table. As you will note, there are three grades assigned from the project Steps-Up instrument: pass, conditional pass, and fail. A rescreening is given to children who received a conditional pass within three months of the first screening date. All children who fail are subsequently referred for a comprehensive evaluation. In 1981-82 and 1982-83 most of the children screened were from low income, minority families from the Porter Leath Family Day Home Services.

Les Passees Volunteer Project for
Developmental Disabilities

1979-83

1979-80 Day Care Centers		1980-81 Day Care Centers		1981-82		1982-83	
Total Screened:	610		209		138		147
Failed:	28	(4.6%)	6		12	(8%)	5 (3%)
Conditional pass:	33		24		14		12
Pass:	549		179		112		130

Les Passees Volunteer project personnel assisted with the initial training of volunteers in North Mississippi through a pilot project conducted in two locations in cooperation with the North Mississippi Methodist Agency for the Developmentally Delayed and the North Mississippi Retardation Center. Thus, the project in North Mississippi was subsequent to the pilot effort of Les Passees Rehabilitation Center and Meharry Medical School.

Widespread understanding and support for early identification of and education for handicapped children is a main goal of both the rural & urban models. Special effort was made to involve minority members of the community as trained volunteers and as focal points for publicity and support in local communities. The North Mississippi Retardation Center is currently collecting data using the Steps-Up screening model that will validate or invalidate the use of the instrument in the hands of trained volunteers; however, final results will be available at a later date.

VII. Future Directions

North Mississippi Retardation Center

Parent-family participation are evident from the beginning of the program, since parents usually bring young children to the screening site, and sign "Release of Information" forms if possible developmental delays are noted. Parent interaction continues in the diagnostic/evaluation and case management process. In the future, parents will be recruited and trained as volunteers for other screening sites. Also, in future years of the program, home-based parent training will be initiated in counties served by the North Mississippi Retardation Center. The curriculum for parent involvement to be used is that developed and used by North Mississippi Retardation Center in Project RUN and Project Outreach - a model home-based stimulation program funded through the U.S. Office of Special Education and Rehabilitation.

Les Passees Rehabilitation Center

It is planned that with more volunteer participation in this project, increased numbers of children will be reached. The Department of Human Services in Memphis provides the family day home service, and by adding these services to the screening program many more children will be reached. In addition, plans are to hold a training week at a neighborhood church, with Les Passees volunteers training the church volunteers. Following the training, there will be a screening weekend open to the public, drawing primarily from those who live in the area of the church. The church volunteers will then be a new "core group" and will be able to continue screening in the community.

Even though Les Passees has a ready made base from which to draw volunteers for this project, much thought has been given to ways in which the developmental screening program can be expanded in Memphis and the surrounding county. Church groups in search of a project that will benefit their community, and can be effectively handled by a small number of volunteers and money, could easily handle a project such as the Steps-Up Developmental Screening Project. College or university sororities and fraternities, community or neighborhood organizations are future resources for volunteers. As long as this screening does not become too technical, nor demand an unrealistic amount of volunteer time and money, it can be presented with acceptance and subsequent success by an interested, committed group within one's community.

FOOTNOTES

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